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ABSTRACT

This annual survey of respite care and crisis nursery programs funded by the Children's Bureau of the Administration for Children, Youth, and Families of the U.S. Department of Health and Human Services contains program information for 43 crisis nursery programs and 65 respite care programs. Data on crisis nurseries and on respite care programs are analyzed in terms of: numbers of persons served, percentages of programs providing services to various family types, types of services provided to children and to parents/caregivers, referral sources, delivery sites, parents' reasons for using the services, problems experienced by children, protective service status of families, substance abuse among families, and fees paid by families. A summary section outlines the need for standardized collection and reporting of data, and compares and contrasts utilization of the two types of programs. A copy of the survey form is provided. (JDD)

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Access to Respite Care and Help

The National Resource Center for Crisis Nurseries and Respite Care Services

RESPITE CARE AND CRISIS NURSERY 1992 ANNUAL PROGRAM SURVEY: FOR SERVICES PROVIDED DURING 1991

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Respite Care and Crisis Nursery Annual Program Survey: for Services Provided During 1991

The Research and Evaluation Component of ARCH, the National Resource Center for Crisis Nurseries and Respite Care Programs, conducts an annual survey of respite care and crisis nursery programs funded by the Children's Bureau of the Administration for Children, Youth, and Families of the US. Department of Health and Human Services through the Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986 (as amended). Surveys are sent to each direct service program with a request for information about services provided during the previous calendar year. The 1992 Respite Care and Crisis Nursery Program Survey requested information on program activities that occurred during the calendar year, 1991. A total of 181 surveys were sent to direct service programs and 108 (60%) completed surveys were returned. There were 43 crisis nursery program surveys and 65 respite care surveys returned. Although it was not possible to learn the reason for the omission of data in all cases, among those surveys for which no data were received, the following reasons were determined: seven were returned with the comment that no services were provided during 1991; in follow-up calls, 20 additional programs reported providing no services, and a few states aggregated data for all the programs in the state onto one survey form. In addition, it must be noted that programs were at different points in the funding cycle, some having been funded in 1989, some in 1990, and others in 1991.

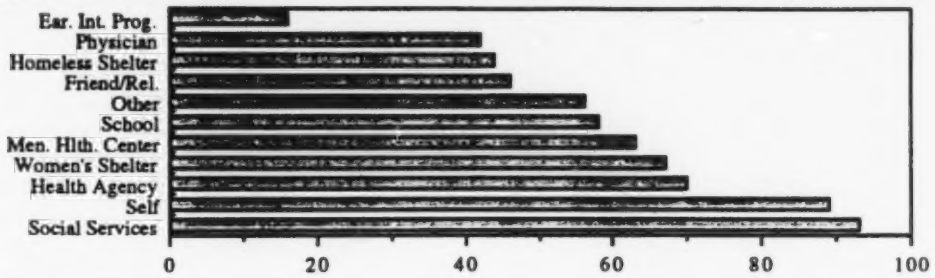
Among the programs that sent completed questionnaires, not all were able to respond to all questions, consequently, the percentage of programs responding will differ from question to question. Due to the wide range of families served, the median will be the statistic reported for most data. Ranges will be included to further clarify the findings. A series of new questions included in this survey were designed to count the number of families and the number of individuals served during 1991. Data were requested on girls, boys, women, and men. The women and men were the caregivers of the children who received services. Not all respondents were able to provide the information sought as they did not collect the data or did not record it in a way that would allow them to respond to the questions. Results reported here will be qualified as needed.

Crisis Nursery Programs

A total of 43 crisis nursery programs returned completed surveys. Of those, 91% served both parents/caregivers and children; while 9% served only children. Services may be provided in the family's home or outside the home. Slightly more than half (60%) of the crisis nurseries reported providing services only outside the home, while the other 40% served families both inside and outside the home.

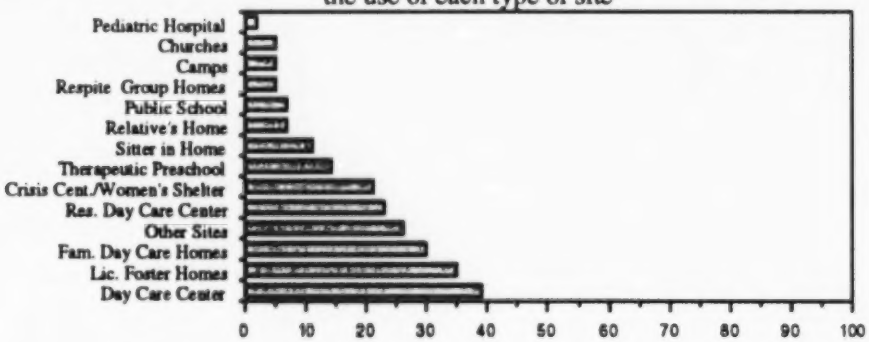
For most programs, referrals came from a variety of sources. Although percentages for each source were sought on the survey, a large number of programs were unable to do more than indicate which sources offered referrals. Consequently, results are reported as the percentage of the 43 programs endorsing each source. As is seen in Figure 1, the overwhelming majority of programs receive referrals from social services. An encouraging sign was the large percentage (79%) of programs reporting that parents/caregivers refer themselves, indicating that parents are seeking help before the situation gets out of hand. As can also be seen in Figure 1, a large proportion of programs receive referrals from shelters. More than 40% from Homeless shelters and nearly 70% from Women's shelters. These data indicate that crisis nurseries are reaching the population that is in greatest need of their services.

Figure 1: Crisis nursery referral sources: Percentage of programs reporting each source



Programs provided services to families in many different sites. Figure 2 lists those sites and the percentage of programs reporting the use of each. As can be seen by the wide variety of settings employed, programs utilize settings available in their community as they attempt to meet the needs of their families. No one site was mentioned by a majority of programs, and two available options, state school and state institution, were reported by none of the respondents.

Figure 2: Sites in which crisis nursery services were delivered: Percentage of programs reporting the use of each type of site



About one fourth of the reporting programs placed parents/caregivers (23%) or children (26%) on a waiting list during 1991. Among those programs that reported the use of waiting lists, the median number of parents/caregivers who were placed on waiting lists was 24, with a range of 4 to 200. The median number of children on waiting lists was 35, with a range of 15-314. Due to the nature of the needs of families using their services, crisis nursery programs attempt to obtain services for families as quickly as possible, and prefer to refer the family to another agency rather than place them on a waiting list.

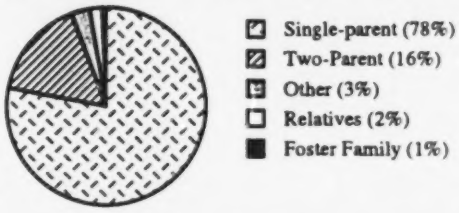
Crisis nurseries serve a variety of family-types. The following table presents the median number of each type of family configuration served, and the percent of programs that report serving those families. As can be seen, more than three quarters of the programs served both single-parent and two-parent families. However, the median number of single-parent families was three times that of two-parent families.

Table 1: Percentage of crisis nurseries providing services to each family-type

Family-Types	% of Programs Reporting	Median # of Families Served	Range
Single-Parent	81	47	1-834
Two-Parent	77	16	1-144
Relatives	37	4	1-17
Foster Family	26	2	1-33
Other	16	4	1-70

Although most crisis nurseries served both single-parent and two-parent families, more than three quarters of the families served were in the category of single-parent families, as is seen in Figure 3 below. Given the considerable pressures on single-parents, this finding is an indication of the stressful situations endured by families using crisis nurseries.

Figure 3: Percentage of each family-type served by crisis nurseries.



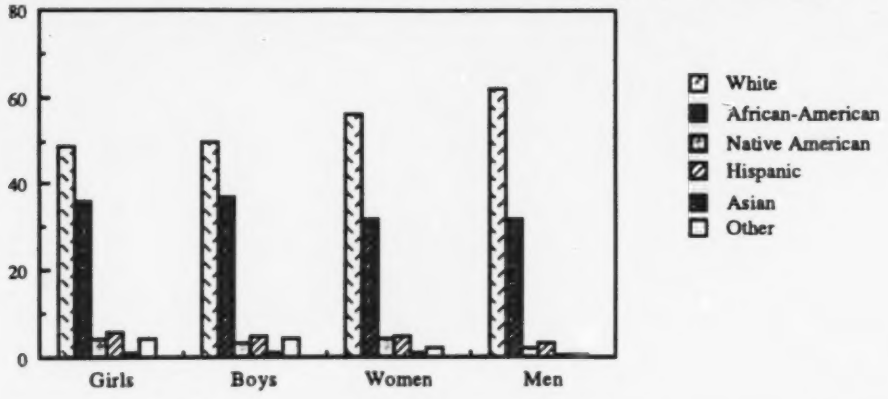
More than 75% of the reporting programs were able to provide information about the numbers of individuals served. While crisis nurseries provided services to parents/caregivers, the majority of their efforts focused on services to children, with a median number of 126 children being served, as can be seen in the Table 2 below. The smallest group was that of Men, which echoes the finding that the largest family-type served was single-parent families, which are often single-mother families. Table 2 presents the percentage of programs providing these data, and the median number of persons served in each category.

Table 2: Number of persons served by crisis nurseries: Percentage of programs reporting and median number served

	% of Programs Reporting	Median # Served	Range		% of Programs Reporting	Median # Served	Range
Parents/caregivers	84	48	3-978	Children	93	126	5-2,495
Women	81	42	2-834	Girls	84	44	3-1,195
Men	77	7	1-144	Boys	84	44	2-1,300

In addition to the number of persons served during 1991, programs were asked to give the race/ethnicity of the persons served. In Figure 4, the percentages of persons served in each group by race/ethnicity are presented. As is seen, the largest percentage of persons served were White, followed by African-American. Among children served, almost half were minorities, predominantly African-American. The categories Women and Men represent the parents/caregivers who received services. Among these groups, more than a third were from minority groups, with the majority of those being African-American. These are percentages only for reporting programs, and may not represent the percentages for all crisis nurseries.

Figure 4: Percentages of persons served by crisis nurseries in each group, by race/ethnicity



When asked on what the figures in the above tables were based, 74% of the programs replied that it was an actual count, 9% indicated that it was an estimate, and the other 16% did not provide the information.

A variety of services are provided to children by crisis nurseries. Table 3 below indicates the percent of programs providing each service, and the median number of children to whom each was provided. Almost three quarters of the programs provided day care, and more than 40% offered overnight care. Programs reported providing essential services to large numbers of children. Among these were screening, furnished to a median of 130 children; assessment, offered to a median of 140; service coordination, supplied to a median of 84 children; and access to medical care which was delivered to a median of 155 children.

Table 3: Percentage of crisis nurseries providing each type of service to children during 1991, and the average number of children receiving each service

Type of Service Provided	% of Programs Reporting	Median # Served	Range
Day Care (center or family home care)	72	65	3-890
Service Coordination	56	84	25-2,495
Screening	47	130	13-2,495
Assessment	44	140	13-2,495
Residential Care (short-term 24 hr care)	44	35	1-2,495
Social/Emotional/Behavior Therapy	35	26	1-890
Access to Medical Care	23	155	1-900
Social or Recreational Programs	14	65	11-1,469
Companionship (mentors)	7	21	10-74
Speech/Language Therapy	7	4	4-24
Occupational Therapy	5	14	4-23
In Child's Home (sitter)	5	48	1-94
Hospital Sitter	2	12	12
Physical Therapy	2	2	2

As with children, programs provided a wide variety of services to parents/caregivers. In the table below are displayed the types of services, the median number of parent/caregivers to whom each was provided, and the percentage of programs offering each service. Half the programs reported offering at least four services other than child care. Among those were services designed to relieve the stress being experienced by families in deteriorating circumstances. For example, hotline or

crisis line services were supplied to a median of 200 parents; service coordination was offered to a median of 52 parents; and telephone consultation to a median of 49 parents. In addition half of the reporting programs offer services designed to increase the skills of parents to cope with life and, specifically, their children through the provision of counseling/therapy and courses on child care and parenting skills. The median number of parents receiving additional services compares very favorable with the median number of parents served by reporting programs (see Table 2).

Table 4: Percentage of crisis nurseries providing each type of service to parents/caregivers during 1991, and the average number of parents/caregivers receiving each service

Type of Service Provided	% of Programs Reporting	Median # Served	Range
Respite from Child Care	63	30	1-978
Service Coordination	56	52	1-1,930
Parent Counseling/Therapy	49	23	2-807
Training in Child Care/Parenting Skills	49	23	5-807
Telephone Consultation	49	49	5-978
Hotline/Crisis Line	35	200	2-3,288
Support Group	28	22	5-378
Access to Medical Care	21	10	1-126
Substance Abuse Counseling	16	8	2-22
Hospital Companion	9	6	1-56
Other	9	8	5-233

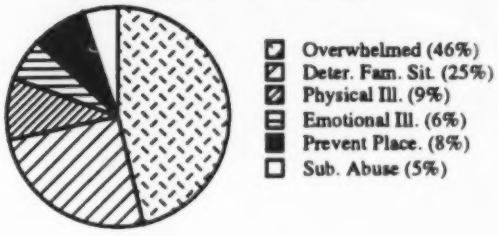
Parents/caregivers may have a number of reasons for accessing crisis nursery services. In Table 5 below are presented the percentage of reporting programs, and the median number of families in each category. More than half the programs reported serving families who were overwhelmed by their life circumstances, or were physically or emotionally ill. Among the families, the largest numbers were reported to be accessing services due to the deteriorating or overwhelming nature of their life situation. In addition, nearly half the programs reported serving families whose reason for accessing services was substance abuse of one type or another.

Table 5: Percentage of programs reporting parents reasons for using crisis nursery services, and average number of families in each category

	% of Programs Reporting	Median # Reported	Range
Parent overwhelmed	72	30	11-661
Deteriorating family situation	58	23	1-244
Parent physically ill	58	4	1-119
Parent emotionally ill	51	6	1-98
Prevent out-of-home placement	49	6	1-195
Parental substance abuse	44	9	2-66

It is clear from the data presented in Figure 5 below that the majority (71%) of parents being served by crisis nurseries were overwhelmed by their life circumstances and/or were experiencing a deteriorating family situation. In addition, as was seen in Table 4, nearly half of reporting programs served parents with substance abuse as a presenting characteristic. Among those individuals, crisis nurseries reported 306 parents (5%) as using their services primarily because of substance abuse. This percentage is two and a half times that of parents using respite care services.

Figure 5: The percentage of parents for whom each of the categories was a primary reason for using the crisis nurseries



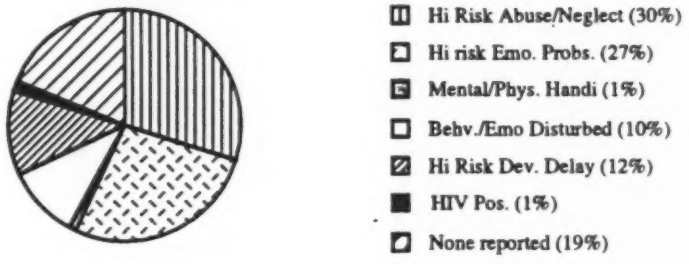
Children receiving crisis nursery services may be experiencing a variety of problems. These are listed below, by the percent of programs reporting each, with the median number of children for whom each was reported to be a primary problem. The majority of programs reported serving children at high risk for abuse/neglect.

Table 6: Problems experienced by children: Percentage of programs reporting having served children with each identified problem, and the average number served

	% of Programs Reporting	Median # Reported	Range
High risk for abuse/neglect	79	56	8-1,746
High risk for emo. problems	47	16	3-166
High risk for dev. delay	44	10	1-110
Behav/emo disturbance	35	7	1-70
Physical handicap	21	2	1-5
None	21	7	1-371
Mental retardation	16	2	1-5
Chronic/terminal illness	9	2	1-12
HIV positive	5	2	2-2

As can be seen in the following figure, children who were served by these 43 crisis nurseries during 1991 were characterized by a number of primary problems. More than half (57%) of children were at risk for abuse/neglect or emotional problems, as was expected based on the mission of crisis nurseries. However, as was true for the parents/caregivers, almost a fifth of the children were experiencing no apparent problems. This finding may stem from the fact that a large number of parents began to use the crisis nursery services on a voluntary basis and may have been doing so to avoid problems for the child. Consequently, at the time of service, the children may have been exhibiting no specific problems.

Figure 6: The percentage of the total number of children served by crisis nurseries as a function of their primary presenting problem.



The program survey requested information concerning the protective services status of the families utilizing crisis nursery programs. As can be seen in the table below, there was considerable variability within the programs. Although more than 60% of the crisis nurseries reported serving families with both known and suspected involvement, more than a third of the families had no known involvement with protective services. This may be a result of the number of families who referred themselves to the programs.

Table 7: Protective services status of families using crisis nurseries

	% of Programs Reporting	Median # Reported	Range	% of Total Families
Substantiated	70	9	1-200	18
Suspected	63	15	1-685	28
None	63	30	12-264	35
Unknown	42	10	2-196	19

The number of families with suspected, substantiated, or unknown substance abuse are listed in Table 8 below. Almost two thirds of the programs reported serving parents/caregivers with suspected substance abuse, and more than half reported serving families with substantiated substance abuse. However, the number of parents/caregivers with substantiated substance abuse was relatively few for any one program. A total of 650 parents (17%) were reported as having substantiated substance abuse, and, as was seen in Figure 5, for almost half this number of parents (306) substance abuse was a primary reason for using crisis nursery services.

Table 8: Substance abuse among families using crisis nursery services

	% of Programs Reporting	Median # Reported	Range	% of Total Families
Suspected	65	8	2-404	32
Unknown	60	22	1-685	50
Substantiated	58	10	1-182	18

Among the crisis nursery programs that responded, the overwhelming majority provided services to families for no cost. Only three programs indicated that any families paid for services. The federal legislation under which these programs receive funding mandates no fees for up to 30 days of service annually

Table 9: Fees paid by families using crisis nursery services

	% of Programs Reporting	Median # Reported	Range	% of Total Families
No fee	77	75	3-978	99.5
Regular fee	5	11	4-18	.4
Low fee	2	1	---	.1

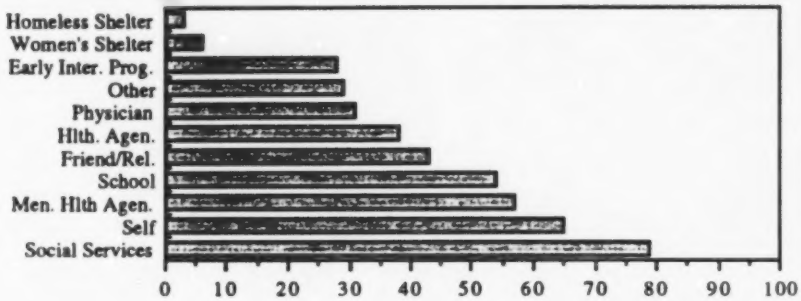
Respite Care Programs

A total of 65 respite care programs returned completed program surveys for the year 1991. Of those, 22% provided services to children only, 2% to parents/caregivers only, and 76% to both children and parents/caregivers. Services were provided only in the family's home by 8% of the respite care programs, only outside the home by 17%, and both in the home and outside by 75%.

Twenty percent of the respite care programs reported placing parents/caregivers on a waiting list during 1991. Among those programs, the median number on a waiting list was 6, with a range of 1-53. Slightly more programs (32%) reported placing a median of 6 children on waiting lists, with a range of 1-245.

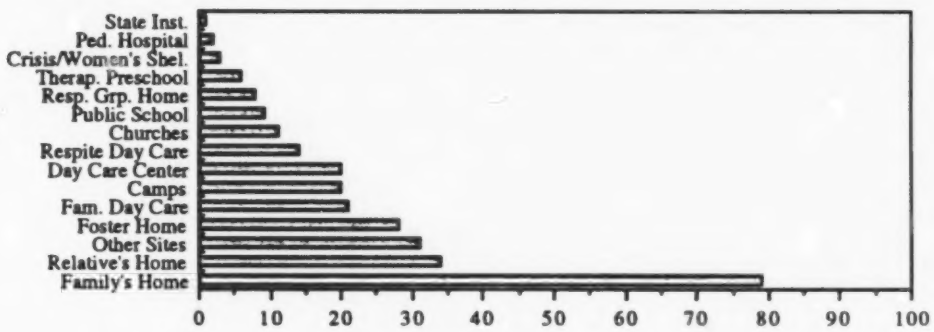
Families began using respite care services through a variety of referral sources. Figure 7 lists those sources and the percentage of the 65 reporting programs which endorsed each. The first two sources reported by respite care programs are the same as those reported by crisis nurseries. An interesting finding here was the large number of programs receiving respite care referrals from social services, particularly in light of the small precentage of families (7%) with substantiated or suspected involvement with protective services (see Table 16). As was seen with crisis nursery families, a sizable percentage of families using respite care programs were self referred.

Figure 7: Respite care referral sources: Percentage of programs reporting each source



Respite care services are delivered in many places throughout the community. Figure 8 lists those sites and the percentage of programs that reported using each type of site. The only site not reported by respite care programs was that of a state school. The majority of programs reported providing an in-home sitter. Given the nature of the population being served, this finding was not unexpected, and parallels the findings of the 1990 survey.

Figure 8: Sites in which respite care services were delivered: Percentage of programs reporting the use of each type of site



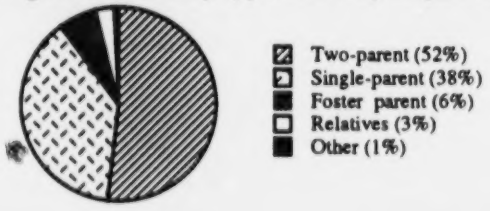
Respite care programs also serve a variety of family-types. The following tables present the median number of each type of family configuration served, and the percentage of programs that report serving those family-types Like crisis nurseries, three quarters of the programs reported serving both single-parent and two-parent families

Table 10: Percentage of respite care programs providing services to each family-type, and average number of each type served

Family Types	% of Programs Reporting	Median # of Families Served	Range
2-Parent	83	13	1-525
Single-Parent	74	10	1-525
Foster Parent	43	3	1-39
Relatives	37	2	1-10
Other	11	2	1-12

As can be seen below, unlike crisis nurseries, respite care programs served more two-parent than single-parent families. This parallels findings from previous program surveys and the site visits.

Figure 9: Percentage of each family-type served by respite care sites



Among the 65 respite care programs responding, 83% were able to provide information about the number of parents/caregivers served during 1991; and, 92% about the number of children served. As can be seen in the table below, respite care programs served fewer persons than did crisis nurseries. However, respite care programs tend to serve families on a long term basis, and, consequently, serve fewer families in a given time period.

Table 11: Number of persons served by respite care programs: Percentage of programs reporting and median number served

	% of Programs Reporting	Median # Served	Range		% of Programs Reporting	Median # Served	Range
Parent/caregivers	83	31	4-350	Children	92	34	2-800
Women	75	18	2-112	Girls	83	15	1-158
Men	74	6	1-70	Boys	89	15	2-142

In addition to the number of persons served during 1991, programs were asked to give the race/ethnicity of the persons served. Figure 10 presents the percentage of persons served in each group by race/ethnicity. As is seen, the largest percentage of persons in each group were White, followed by African American. A comparison of Figures 4 and 11 reveals that among children served by crisis nurseries 50% had minority status, while only 40% of the children in respite care programs were minorities. As was found with crisis nurseries, the largest percentage of those with minority status were African-American. The categories Women and Men consist of the parents/caregivers of the children receiving services. These are percentages only for reporting programs, and may not represent the percentages for all respite care programs.

Figure 10: Percentage of persons served by respite care programs in each group by race/ethnicity

When asked on what the data for the above were based, 85% reported it was an actual count, and 5% that it was an estimate. Among the 10% of the programs that did not provide these data, 5% responded that they did not gather this information and 5% did not respond to the question.

Respite care programs provide a variety of services to children. The table below indicates the percentage of programs providing each type of service, and the median number of children to whom each was provided. As was expected, the majority of programs provided respite in the form of a sitter in the child's home, although more than a quarter of the programs also reported using day care centers or family day care homes. Unlike crisis nurseries where at least a third of the programs reported furnishing five additional services to children, only a quarter of the respite care programs offered four additional services. Service coordination, offered to a median of 30 children, and assessment, provided to a median of 41 children, represent the kinds of allied services supplied to children by respite care programs. Therapies - speech, occupational and physical - were offered by relatively few programs, but were supplied to sizable numbers of children by those programs.

Table 12: Percentage of respite care programs providing each types of service to children during 1991, and the average number of children receiving each service

Type of Service Provided	% of Programs Reporting	Median # Served	Range
In Child's Home (sitter)	65	39	1-760
Service Coordination	32	30	4-242
Day Care (center or family home care)	28	8	2-76
Residential Care (short-term 24 hr care)	29	10	2-138
Assessment	26	41	4-175
Social or Recreational Programs	21	11	1-76
Screening	20	15	4-82
Hospital Sitter	14	1	1-24
Companionship (mentors)	12	8	4-69
Physical Therapy	5	37	4-54
Speech/Language Therapy	5	56	5-147
Social/Emotional/Behavior Therapy	5	7	2-49
Occupational Therapy	3	70	5-135
Access to Medical Care	1	3	-

As with children, programs offered a wide variety of services to parents/caregivers. In the table below are displayed the percent of programs reporting each type of service, and the median number of parents/caregivers to whom each was provided. The number of programs that reported offering services other than respite care was less than a third, in contrast to crisis nurseries in which half reported offering at least four additional services. Among crisis nurseries, 16% reported providing substance abuse counseling to parents/caregivers, while, among respite care programs in this sample, none provided substance abuse counseling to families using their services. This may be related to the small number of parents using respite care who report substance abuse as a problem (see Table 15). Overall, relative to the median number of families served by respite care programs, the median number of families receiving additional support services was high (see Table 11).

Table 13: Percentage of respite care programs providing each type of service to parents/caregivers during 1991, and the average number of parents/caregivers receiving each type of service

Type of Service Provided	% of Programs Reporting	Median # Served	Range
Respite from Child Care	74	32	1-185
Telephone Consultation	29	22	2-175
Service Coordination	28	18	3-226
Support Group	21	12	1-40
Training in Child Care/Parenting Skills	17	25	2-55
Parent Counseling/Therapy	11	10	3-47
Hospital Companion	8	1	1-12
Access Medical Care	8	31	1-96
Other (specify)	6	28	3-47
Hotline/Crisis Line	1	5	-
Substance Abuse Counseling	0		

Parents/caregivers may have a variety of reasons for using the services of a respite care program. In Table 14 below are a list of reasons, the percent of programs reporting each, and the median number of families for whom each was reported to be a primary reason for using respite care services. Almost three quarters of the programs reported serving families who were overwhelmed with their situation. While this same reason was given for accessing crisis nurseries, the basis for the finding may differ considerably. In the case of families using respite care, the source of stress is often the child with chronic illness or disabilities, while families using crisis nurseries often have more varied and pervasive sources of stress. A very small percentage of respite care programs reported serving parents who accessed their services because of substance abuse, another difference between respite care and crisis nursery families.

Table 14: Reasons parents used respite care services: Percentage of programs reporting each reason and the median number of families for which each reason was reported

Reasons for Use	% of Programs Reporting	Median # Reported	Range
Parent overwhelmed	72	17	1-139
Deteriorating family situation	41	3	1-139
Prevent out-of-home placement	34	4	1-107
Parent physically ill	26	2	1-10
Parent emotionally ill	15	2	1-3
Parental substance abuse	9	4	1-15

Presented below are the percentages of the total number of parents for whom each listed reason was a primary reason for accessing respite care services. The largest percentage of parents used respite care to alleviate their feelings of being overwhelmed. Few parents (34 or 2%) were

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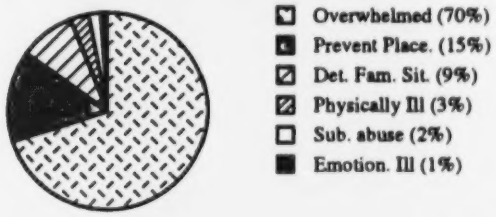
reported to be using respite care services primarily due to substance abuse. This percentage is less than half that reported for crisis nurseries.

Figure 11: The percentage of parents for whom each of the categories was a primary reason for using respite care services



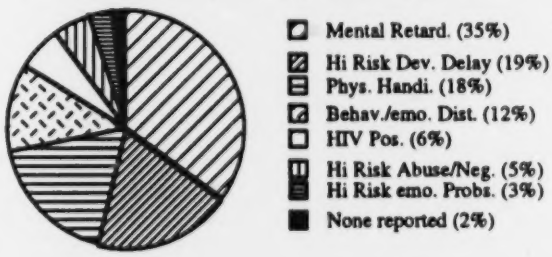
Children receiving respite care services may be experiencing a variety of problems. These are listed below, with the percent of programs reporting each, and the median number of children in each category. The nature of the mission of the respite care programs is mirrored by the problems of the children they serve. As is seen below, most programs serve children with mental and emotional problems, and a sizable number serve children who are at-risk for developmental delay or are experiencing physical handicaps. The median number of children reported to be HIV Positive was 18, the largest median reported. The four programs reporting this number are those that target children who are HIV Positive. These programs provide an important service to families who have a difficult time finding trained caregivers for their ill children.

Table 15: Problems experienced by children using respite care services

Child Conditions	% of Programs Reporting	Median # Reported	Range
Mental retardation	55	9	1-350
Behav/emo disturbance	55	7	1-60
High risk for dev. delay	49	7	1-73
Physical handicap	43	3	1-172
Chronic/terminal illness	33	2	1-27
High risk emo. problems	23	3	1-24
High risk for abuse/neglect	19	2	1-69
None reported	9	5	1-32
HIV positive	6	18	2-42

As is seen below, children served by respite care programs are characterized by a variety of problems. Almost three quarters (72%) of the children are described as having cognitive or physical disabilities or delay.

Figure 12: The percentage of the total number of children served by respite care programs as a function of their primary presenting problems



The program survey requested information concerning the protective services status of the families utilizing respite care programs. As can be seen in the Table 16 below, 25% or fewer of the programs served families known to be involved with protective services, and only seven percent of the families known or suspected involvement with protective services.

Table 16: Protective services status of families using respite care services

	% of Programs Reporting	Median # Reported	Range	% of Total Families
None	46	18	2-255	55
Suspected	25	2	1-15	3
Substantiated	23	2	1-26	4
Unknown	11	6	1-1,050	38

The number of families with suspected, substantiated, or unknown substance abuse are listed in the table below. The information in Table 17 indicates that less than a fifth of the programs reported serving families with suspected or known substance abuse, and only 40 (3%) of the families had known substance abuse. This number is only a sixth of the percentage of crisis nursery families.

Table 17: Substance abuse among families using respite care services

	% of Programs Reporting	Median # Reported	Range	% of Total Families
Unknown	37	18	1-248	91
Suspected	21	2	1-23	6
Substantiated	10	3	1-15	3

As part of the federal program's requirements, respite care services are required to set fees for services and use a sliding fee scale. A third of the 65 reporting programs indicated that families paid a low fee, and 17% that families paid the full, regular fee. Among the total number of families, 65% paid a low or regular fee. This finding is consistent with the results of the site visits which found families using respite care services more often to be two-parent families, and to be better educated and have higher paying jobs than families using crisis nurseries.

Table 18: Fees paid by families using respite care services

	% of Programs Reporting	Median # Reported	Range	% of Total Families
No fee	40	18	1-176	35
Low fee	34	6	1-893	55
Regular fee	17	8	0-79	10

Staff

In addition to information about families, the survey gathered information about the individuals who staffed the programs. During 1991, reporting crisis nurseries were served by 421 staff members, and respite care programs by 433 staff members.

Within the crisis nurseries staff, 90% were women, among whom 64% were White, 19% were African American, 13% Hispanic, and less than 2% were either American Indian, Asian, or Other.

All of the staff had at least a High School degree, with 59% having a Bachelor's or Master's. Crisis nurseries staff had an average of six and a half years of experience in human services, with a range from just starting to 30 years. They worked an average of 31 hours a week, ranging from less than an hour to 48 hours. The largest number of staff are those who provide direct care to the children, 42%, and the next, 17%, were identified as program directors or coordinators. In addition to these two groups, there were listed aides, therapists, support staff, nurses, social workers, and others.

The demographics for respite care staff were almost identical to those of the crisis nurseries, with staff being predominately female, 88%. The racial/ethnic distribution was also very similar, 66% being White, 20% African American, 7% Hispanic, and a small number American Indian, Asian, or Other. All staff had at least a High School degree, with 50% having a Bachelor's, Master's, or Doctorate. Respite care staff had a mean of eight years of human services experience, with a range of new to 30 years. The greatest difference between the two program staffs was in the number of hours worked per week. More respite care workers were part-timers who worked an average of 19 hours a week, ranging from half an hour to 50 hours. The largest percentage of staff were child care providers, 45%, and program directors or coordinators, 18%. Among the others were care coordinators, social workers, nursing aides, therapists, and support staff.

A question was included that asked about salary source, in an attempt to learn how many staff were paid from Children's Bureau funds. Unfortunately, for most programs, monies are so combined that it was difficult, if not impossible, for programs to determine to whom specific funds were channeled.

Summary

This survey was the first attempt to get a count of the number of persons served by both crisis nurseries and respite care programs. It appears, from the responses, that a number of programs do not maintain those data. For example, of the 65 respite care programs which returned completed surveys, 17% were unable to respond when asked how many parents/caregivers they served; 25% could not tell the number of parents/caregivers who were women and 26% the number of parents/caregivers who were men. This same pattern was repeated for crisis nurseries. In addition, for some programs, the count is a duplicated count. The new data management program, PACERS, Program and Client Event Recording System, will be made available to all programs, in both paper and pencil, and computer versions. It is hoped that in the future, a more accurate count will be obtainable through the annual survey by using PACERS.

One of the major differences between respite care and crisis nursery programs is in the number of persons served during 1991. Crisis nurseries serve many more caregivers and children than do respite care programs. This finding fits well with the kinds of families each serves. Families with a child who has a disability or chronic illness, continue to need the services of the respite care program on an ongoing and regular basis. Many families who use crisis nursery services, on the other hand, use the program once or twice, or on an irregular basis. This difference means that, during a year, crisis nurseries will provide services to many more different persons than will respite care programs. Turn-over of those served at the respite care programs is slower, and fewer programs keep waiting lists since openings occur less often.

Both types of programs provide respite care to parents/caregivers. The site of the child care is another major difference between the programs. Respite care programs are more likely to provide child care in the family's home, while crisis nurseries offer child care in day care centers or homes, or residential settings. Another service difference is in the percentage of programs offering other services than child care to parent/caregivers. Fewer than a third of the respite programs offer other services, while more than a third of crisis nurseries offer several other services. This may be a

reflection of the fact that families using crisis nurseries may be in need of more services. It is interesting to note the high percentage of crisis programs that provide service coordination to parents/caregivers and children This may also be a function of the greater number of needs experienced by these families.

Almost three quarters of the programs reported families using respite care and crisis nursery services were doing so primarily because the parents/caregivers were overwhelmed. However, the source of the distress is likely to be different between the two sets of families. This is emphasized by the higher number of families from crisis nurseries who are HIV Positive, have substantiated substance abuse, and are known to be involved with protective services, compared to those using respite care programs. In addition, higher percentages of crisis nurseries had parents in all other reason-for-use categories, again, underscoring the greater needs of these families. Another indicator of the degree of need experienced by families served by crisis nurseries is the high percentage of programs which reported receiving referrals from shelters (Figure 1) in contrast to those received by respite care programs (Figure 7). Families utilizing shelters often lack the most basic necessities of life. The services of a crisis nursery can offer parents a safe place for their children as they cope with daily living. In addition, problems experienced by the children were quite different between the programs, with the majority of those in respite care programs being characterized with developmental difficulties, while the children in the crisis nurseries were far more likely to be at risk of abuse and/or neglect. However, a sizable proportion of those in crisis nurseries were at risk for developmental delays. These may be another manifestation of the stresses existing in the lives of these children

There were striking differences between the two sets of programs in respect to the protective services status and substance abuse among families served. A very small percentage (6%) of parents using respite care services were reported to have suspected or substantiated involvement with protective services, while almost half (46%) of the families using the crisis nurseries had known or suspected protective services involvement. Families using crisis nurseries were four times as likely to have substantiated involvement with protective services, and six times as likely to have substantiated substance abuse. In addition, more than 18% of families in the crisis nurseries had substantiated substance abuse, while for only 4% of the respite care families was this true. These findings provide additional indication that families using crisis nurseries are in need of a variety of supports.

Within both sets of programs, more than 90% of the children served were in two-parent or single-parent families, as opposed to being with relatives, in foster care, or in other situations. On the other hand, the proportion of two-parent to single-parent families was quite different. Crisis nurseries served only a third as many two-parent families as did respite care programs and twice as many single-parent families. Based on what is known about the needs of single-parent families, it is likely that a large number of the families utilizing crisis nurseries will require additional services. The results from the survey indicate that the crisis nurseries in this group are making every effort to meet these varied needs. While the majority of both respite care and crisis nursery programs offer child care, more than a third of the crisis nurseries offer a variety of additional services to both children and parents/caregivers. A situation which is less true among the respite care programs.

The results of this survey indicate that respite care and crisis nursery programs also served somewhat different populations from a racial/ethnic view point. Crisis nurseries serve more individual of racial/ethnic minority status than do respite care programs. The majority of these, among both children and parents, were African-American, as can be seen in Tables 4 and 10. This difference may be representative of families who are experiencing difficult circumstances and access the services offered by crisis nurseries to help cope with their life

It is clear from these findings that families using crisis nursery services are in experiencing greater stress and disorganization in their lives. Many access the services of crisis nurseries in their efforts

to provide for their children; many more are referred to these services by other organizations. The many services offered by crisis nurseries are essential to the well being and growth of these families.

There were few differences between the staff at the two sets of programs. Staff were predominately female, White, and direct service providers. The major difference seems to be that respite care workers are more likely to be part-time workers than are crisis nursery staff. These are the same findings that have emerged from the previous surveys.

The findings presented in this report are based on relatively small sample of respite care and crisis nursery programs receiving these federal grant funds They are not intended to be representative of all programs, but to offer a glimpse of the kinds of services that are available to families in need of support, and to describe some of those families and children.

APPENDIX

Access to Respite Care and Help

The National Resource Center for Crisis Nurseries and Respite Care Services

PROGRAM DESCRIPTION SURVEY
CRISIS NURSERY/RESPITE CARE DEMONSTRATION PROJECTS

This survey is designed to be completed by a direct service program providing Crisis Nursery or Respite Care services. Funding for these services comes from the Children's Bureau in Washington, DC to a state agency; and from a state agency to a direct service program. Your program may receive funds from a variety of sources, however, we are particularly interested in services that are paid for by Children's Bureau funds. Please keep this in mind as you complete the survey.

The information on the survey should cover the time period January 1, 1992 through December 31, 1992.

NOTE: If your program did not serve any families during calendar year 1992, please complete only questions 1, 2, 3, and 4, and return the survey.

Please complete this Program Survey and return it in the enclosed stamped, addressed envelope by **1 May, 1993** If you have any questions about the survey, call Kris Huntington or Lisa McVicker at 919-966-5038, the ARCH Research and Evaluation Office.

Kris Huntington and David Langmeyer

Research and Evaluation Component, The ARCH National Resource Center for Crisis Nurseries and Respite Care Programs, FPGCDC, CB# 8180, UNC-CH, Chapel Hill, NC 27599

SECTION A - Administrative Characteristics of the Program

1. Type of grant received: _____ Crisis Nursery _____ Respite Care

2. Name and address of program under which grant operates:

3. Name and telephone number of person primarily responsible for grant activities:

4. **If your program did not serve families during 1992, check here and return the survey** _____

5. Services were provided to: (CIRCLE ONE)

   a: children only
   b: parents/caregivers only
   c: both children and parents/caregivers

6. Services were delivered: (CIRCLE ONE)

   a: only within parent's/caregiver's home
   b: only outside parent's/caregiver's home
   c: in both settings

7. Sources that referred families/children to your program: Please check all that apply. Indicate source of most frequent referrals with an asterisk.(*).

   - ☐ Self
   - ☐ Physician
   - ☐ Social Services
   - ☐ Mental Health Agency
   - ☐ Health Agency
   - ☐ Other (Specify)
   - ☐ Friend/Relative
   - ☐ Women's Shelter
   - ☐ Homeless Shelter
   - ☐ School
   - ☐ Early Intervention Program

8. Programs may provide services in a variety of settings. Place a check in front of each type of setting your program used during 1992.

- ☐ Licensed foster home (24 hr.)
- ☐ Relatives' home
- ☐ Respite group homes
- ☐ Respite day care center
- ☐ Therapeutic preschool
- ☐ State institution (respite bed)
- ☐ Camps
- ☐ Public schools
- ☐ Other (please specify _____)
- ☐ Family day care homes (daytime)
- ☐ Home of sitter/respite or crisis care provider
- ☐ Crisis centers/nurseries
- ☐ General purpose day care center
- ☐ Pediatric hospital (respite bed)
- ☐ State school
- ☐ Church
- ☐ Women's/Homeless shelters
- ☐ Family's home

Section B: Service Population Description

The following section is designed to gather information about those served by your program during 1992. We would like to know how many families you served, how many of the people in those families were children and how many were parents or caregivers. Because some program do not keep data in that way, most of the question will ask for information on families **or** individuals. Individuals is defined as children, and/or parents/caregivers. If your program maintains information on families **and** individuals, please indicate that by answering both Questions 9 and 10. Wherever possible, please provide information on individuals.

9. How many **families** were served by your program from 1/1/92 through 12/31/92? _____
Note, this is not how many individuals but how many families.

10. How many **individuals** were served by your program from during 1992? _____

If your program does not keep data on parents and children separately, check here, and go on to Question 11 _____.
Other wise, please indicate below the number of parents or caregivers, and the number of children who were served by your program during 1992

How many parents/caregivers? _____ How many children? _____

11. Did your program maintain a waiting list during 1992? _____ no _____ yes

If yes, please indicate the number of families or the number of individuals on the list during 1992

Families _____ Individuals _____

12 What was the average length of time spent on a waiting list? _____

13. Sometimes programs are unable to provide services to a family. What does your program do in those cases?

14. Do you document the number of families and/or individuals you are unable to serve?

_____yes _____ no

If yes, please indicate either the number of families or the number of individuals you were unable to serve during 1992.

_____ Number of families _____ Number of individuals

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15. **How many** of each of these general "types" of families did your program serve during 1992?

a: _____ two-parent b: _____ single parent

c: _____ foster parent d: _____ relatives

e: _____ adoptive parents f: other (please specify): _____

16. What was the racial makeup of the **parents/caregivers** noted in Question 10? Please give the number of each race/ethnicity listed below. (**Note-** if your program does not keep separate data for parents/caregivers and children, please complete this question for the **families** in #9)

		We are unable to answer this question because:
African American	_____	
White	_____	_____
American Indian	_____	_____
Hispanic Origin	_____	_____
Asian	_____	
Other	_____	
Total	_____	

If total does not agree with the number given for Questions 9 or 10, please explain.

17. What is the racial make up of the **children** noted in Question 10? Please give the number of children of each race/ethnicity listed below.

		We are unable to answer this question because:
African American	_____	
White	_____	_____
American Indian	_____	_____
Hispanic Origin	_____	_____
Asian	_____	
Other	_____	
Total	_____	

If total of Question 17 does not agree with the number given in Question 10, please explain.

18. Because it is sometimes difficult to arrive at the figures included in Questions 9-17, we would appreciate knowing what they are based on. That is, are they an estimate? If so, what is the estimate based on? Are they an actual count? If so, how are the numbers arrived at?

SECTION C: Types of Services Provided by Program:

19. Programs provide a wide variety of services to **children**. On the table below, please indicate the types of services your program provided to children during 1992

Place a check before each service provided

- ☐ Screening
- ☐ Assessment
- ☐ Service Coordination
- ☐ Access to Medical Care
- ☐ Hospital Sitter
- ☐ Physical Therapy
- ☐ Occupational Therapy
- ☐ Speech/Language Therapy
- ☐ Social/Emotional/Behavior Therapy
- ☐ Day Care (center or family home care)
- ☐ Residential Care (short-term 24 hr. care)
- ☐ Companionship (mentors)
- ☐ Social or Recreational Programs
- ☐ In Child's Home (sitter)
- ☐ Other, please specify

20. As with children, programs provide a wide variety of services to **parents/caregivers.** On the table below, please indicate the types of services your program provided to parents/caregivers during 1992

Place a check before each service provided

- ☐ Parent Counseling/Therapy
- ☐ Service Coordination
- ☐ Telephone Consultation
- ☐ Hotline/Crisis Line
- ☐ Training in Child Care/Parenting Skills
- ☐ Support Group
- ☐ Respite from Child Care
- ☐ Access to Medical Care
- ☐ Hospital Companion
- ☐ Substance Abuse Counseling
- ☐ Other (specify)

21. **Parents/caregivers** may have a variety of reasons for accessing services. Listed below are some possible reasons. For each, please indicate for **how many** parents/caregivers included in Questions 9 or 10 this was the primary reason for receiving services, for how many it was a secondary reason.

	Primary	Secondary
Deteriorating family situation	_____	_____
Prevent out of home placement	_____	_____
Parent physically ill	_____	_____
Parent emotionally ill	_____	_____
Parental substance abuse	_____	_____
Parent overwhelmed/need a break	_____	_____
Parents needed time to take care of family needs.	_____	_____

22. **Children** being served by crisis or respite programs may have a variety of problems. For the children included in the count in Question 9 or 10, please indicate the **number** for whom the following conditions were primary problems, and for how many they were secondary problems.

	Primary	Secondary
High risk for developmental delay	_____	_____
High risk for emotional problems	_____	_____
Behavioral/emotional disabilities	_____	_____
Mental retardation	_____	_____
Physical disability	_____	_____
Chronic/terminal illness	_____	_____
High-risk for abuse/neglect	_____	_____
Documented abuse/neglect	_____	_____
HIV Positive/AIDS	_____	_____
Central nervous system disorder	_____	_____
Injury or accident related disability	_____	_____
Sensory disability	_____	_____
None	_____	

23. Please indicate the **protective service status** of the families included in Question 9a by indicating the number of families that fall into each of the following categories.

Not involved with protective services _____ Status unknown _____

Suspected abuse/neglect _____ Substantiated abuse/neglect _____

24. One factor that may be present in families your program has served is that of **substance abuse.** Please indicate the number of families included in Questions 9 or 10 above, who fall into each of the following categories.
No substance abuse _____ Status unknown _____

Suspected _____ Substantiated _____

25. Of the families served by your program from 1/1/92 to 12/31/92, how many fell into each of the following payment groups?

Paid no fee _____ Paid low fee _____ Paid regular fee _____

26. Please indicate the number of **parents/caregivers and the number of children** served by your program in 1992 who fell into each category listed below.

HIV Positive: Parents/caregivers _____ Children _____

AIDS Parents/caregivers _____ Children _____

SECTION D: Community Activities

27. Respite Care and Crisis Nursery Programs engage in a variety of community activities- educational, informational, and service. Please check all the activities your program was involved in during 1992, and add any we did not include.

- ☐ Publish program newsletter
- ☐ Provide promotional materials
- ☐ Public Service Anouncements - Radio
- ☐ Public Service Announcements - TV
- ☐ Parenting programs for general public
- ☐ Lending library for general public
- ☐ Funding Activities
- ☐ Educational videos
- ☐ Informational videos
- ☐ Newspaper Coverage
- ☐ Public speaking

_____

SECTION E: Services Cost

The next few questions are the beginnings of an examination of the cost of respite care and crisis nursery services. The next step will include contacting programs in order to gain more detailed knowledge of the methods used in cost finding. Programs which do not yet keep cost data, will be offered technical assistance in developing cost finding systems.

28. Does your respite care or crisis nursery program calculate the unit cost of services provided?

Yes _____ No _____

If No, go on to Question 31, if Yes, continue.

29. What is the most recent year for which service costs were calculated? _____

30 Please complete the following table for all the services your program provides . List each service by name, indicate the unit on which cost is calculated (week, day, hour, minute, or whatever unit you use), indicate whether cost is calculated as a function of staff or client time, and, in the last column, give the calculated cost per unit for providing that service.

Name of Service	Unit of Service (week, day, hour, minute, etc)	Staff or Client Activity	Calculated Cost

SECTION F: Description of Project Staff

31. It would be helpful to have a picture of the staffing of your program. Please complete the table below utilizing the codes provided. **List by position title,** not by name

Position Title e.g. respite care provider, secretary, program director, etc. DO NOT GIVE NAMES OF INDIVIDUALS, JUST POSITION TITLES.	Degree: 1=HS 2=AA 3=Bachelors 4=Masters 5=Doctorate	Experience # of years of human services experience	Race 1=Afr. Amer. 2=White 3=Amer. Ind. 4=Hispanic 5=Asian 6=Other	Sex 1=Female 2=Male	Work Hours Hours worked per week